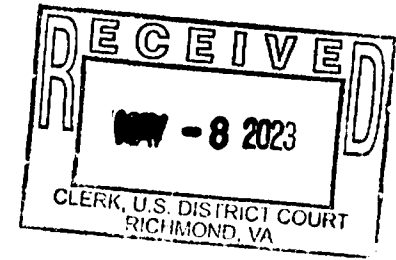


May 3, 2023

The Honorable John A. Gibney Jr.
701 East Broad Street,
Richmond, VA 23219



Dear Judge Gibney,

More than a decade ago, the Commonwealth of Virginia entered into a settlement agreement with the U.S. Department of Justice (DOJ) to ensure Virginians with developmental disabilities had access to high-quality community-based services. The Consent Decree between the DOJ and Virginia was originally set to expire on June 30, 2021. But because Virginia had failed to meet all the requirements set forth in the decree, the federal court extended the date to December 2023. Virginia's goal is to exit the agreement by December 2023. I am writing to you to express concerns about the settlement and its inadequacy of monitoring systems, transparency, and assurances of health and safety for people with the most complex needs. I feel very strongly that the Commonwealth of Virginia is not ready to end the settlement agreement.

My son, Alex, is 17-years-old, has a developmental disability, and is medically complex. He has apraxia and self-identifies as a non-speaking autistic. He is in all general education classes at his neighborhood high school and is an honor roll student. His goals are to go to college, be a mathematician, live independently (with supports), and 'find the woman of my dreams.' However, in reviewing the data from the DOJ settlement, I believe there are multiple areas of concern. First, as seen in the screen shot below, the number of people living independently is not nearly enough- the target was 1,866 and the actual is only 1,654.

Independent Housing

Number of People Living Independently

	Target	Actual Outcome	Target	Actual Outcome
Fiscal Year	Proposed Number of people in Settlement Agreement Population living in Independent Housing each FY	Number of people in Settlement Agreement Population living in Independent Housing each FY	Cumulative Number of people in the Settlement Agreement population living in Independent Housing by Fiscal Year	Cumulative Number of people in Settlement Agreement population living in Independent housing each Fiscal Year
Baseline	341	341	341	28
FY 2015	30	30	373	371
FY 2016	20	101	393	472
FY 2017	41	193	434	665
FY 2018	157	142	591	807
FY 2019	205	147	796	954
FY 2020	409	422	1,205	1,376
FY 2021	661	278	1,866	

As I stated before, my son has complex medical needs. He has a rare syndrome, Oculo Dento Digital Dysplasia (estimated to affect 1 in 12 million), seizures, multiple dental complications, and a Chiari Malformation. As seen in the screen shot below, the independent reviewer's look behind in 2022 for people with complex medical needs (like my son) fell very short in many areas (highlighted in the red box below). The negative data are extremely concerning to families like mine.

People with Complex Medical Needs

VA's Review (QSR): 57 people with complex medical needs for services provided from Jan - June 2021. Review conducted Nov 2021 - May 2022.

Independent Reviewer's (IR's) Look Behind: 32 of those 57 people, which allowed a generalized sample. Look behind review conducted Sept - Oct 2022.

Positive:

- The IR's nurse consultants agreed with the QSR reviewers that there were no unmet healthcare needs for 10 of the 32 people.

Negative:

- Of the 15 people his nurse consultants identified as needing dental care, the QSR reviewers did not identify 11.
- Of the 7 people his nurse consultants identified as needing clinical assessments or consultations, the QSR reviewers did not identify 6.
- Of the 5 people's ISPs that needed modification due to new or changed service needs, the QSR reviewers did not identify the 2 that had not been modified.

* Numerous requested documents were not provided/ not provided in a timely manner. Therefore, it is possible that certain identified discrepancies in the respective findings were not actually discrepancies in fact but were the result of inconsistent sources of information.

One last point I will make is regarding the compliance indicators #7.20 and #29.21 for people with complex behavioral needs. It is alarming to me that only 41% were found to be adequate (target was 86%) for total number of people identified who needed Therapeutic Consultation in their ISP and how many of those people actually received it.

Source: Behavioral Supports Report found DOJ LIBRARY
<https://doj.settlementagreement.org/nia.gov/doj/application/provision/c.6.a/>

People with Complex Behavioral Needs

Compliance Indicator #7.20 & #29.21:

First, DBHDS will report the total number of people identified who needed Therapeutic Consultation in their ISP and how many of those people actually *received it*.

Second: At least 86% of people who need behavioral support services will receive the services that are "adequate and appropriately delivered," (i.e. good quality) using a behavioral quality tool.

OUTCOME:

- #1 – No data. It was expected Nov. 2022 but DBHDS needed a unique billing code which it only created in September 2022.
- #2
 - FY22 Q3: Based on 100 sets of Therapeutic Consultation records = 13% (13/100) were adequate
 - FY23 Q1: Based on 100 sets of Therapeutic Consultation records = 41% (41/100) were adequate

Again, I feel very strongly that the Commonwealth of Virginia is not ready to end the settlement agreement. As the presiding judge monitoring this settlement, I implore you to extend (again) the date of decree for this settlement so Virginia can meet the multitude of targets it has not met to date.

Thank you for your time and attention. Please do not hesitate to contact me with questions or requests.

Sincerely,

A handwritten signature in black ink that reads "Allison Thurman". The script is cursive and fluid.

Allison Thurman
404 Short Street
Ashland, VA 23005
804.240.1707

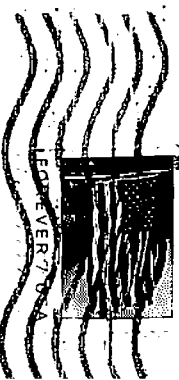
Allison Thurman
704 Short St.
Ashland, VA
23005

The Honorable John A. Gibley, Jr.
701 East Broad Street
Richmond, VA
23219

INSPECTED

MAY 20 2023 PM 4 L

RICHMOND VA 230



April 26, 2023
809 Maybeury Dr,
Henrico, VA 23229

To Honorable Judge John A. Gibney Jr.

I'm writing to inform you how DMAS consistently prevents persons with disabilities from choosing who to hire as attendants and how repeatedly they force people to live in poverty or be forced into a group home against their will.

I will present our situation, prove how DMAS is claiming one thing on their website and doing another in real life, and how this impacts the individual with disability and his already fragile support system.

Our Situation:

I'm a mother of a 19 year old man with genetic disorder, multiple disabilities and global delay. He has mental, emotional and physical needs. We have taken care of him for the last 19 years and although it's been emotionally and financially hard we knew that home was the best place for him to be. Ruben is fully dependent on others for every single part of his life. He needs g-tube feeds and medicine administration, help with bathing and self care, help with walking and navigating safely in all environments, he is non-verbal and uses American Sign Language to communicate and requires someone with ASL skills to take care of him (both parents have taken lessons to learn enough to communicate with him), he wakes up at night sometimes multiple times and needs to be tended to, he has multiple doctors, therapists and specialists that he sees. ---

Every single part of our lives revolves around him and his needs, yet we are willing to do it because we understand that this is the best environment for him. It's not easy and it's very stressful but we desire for him to be at a place where he is safe, is able to communicate and is understood and where he is part of the community.

DMAS Claims:

According to the DMAS website those are goals that should be followed, HOWEVER in practice they ARE NOT!

Medicaid claims that waivers are "*Home and community based*" and that "*Consumer-directed (CD) services is a model of service delivery that empowers the member receiving services to employ an attendant to provide care. Waiver members may choose either consumer-directed or agency-directed care, or both.*" THAT IS NOT TRUE.

Recently DMAS has made it very difficult for parents to take care of their children whether they are adults or minors. DMAS has repeatedly not allowed the "member receiving care" to employ a parent and have denied hours to a parent/attendant. They don't give the member the right to choose but rather keep the decision for themselves. Evaluations for approval happen yearly and we as paid caregivers never know how many hours we will be approved for, if we even will have any hours. We and our loved ones are at the mercy of DMAS.

I've been my son's attendant for the last few years (Covid provision allowed me to take care of him before he turned 18). Till then we were a one income family, which is financially really hard. Trying to find reliable help for an individual with multiple disabilities is EXTREMELY DIFFICULT. The only people who get Cardinal Care waiver and all the waivers that fall under the umbrella are individuals with severe and multiple disabilities. We all have family members who have very serious needs. Finding someone who would work for \$12.70 p/h is almost impossible.

Impact on support system:

Currently we have allotted 56 h a week of care. My husband is the unpaid caregiver and helps with the rest, or I work without pay as our son needs around the clock care which is 168 h a week. Our 15 year old son helps with the care as well, as there are so many things that need to be accomplished.

My son with DD also requires g-tube feedings and medicaid will not pay an attendant for that, therefore I have to clock in and out for every feed I administer. This will NEVER CHANGE. We will take care of our son till he dies, or till we die first. I understand that parents are responsible for taking care of their child, but this is way beyond the regular responsibilities of a parent. If I'm not allowed to work as the paid caregiver or if my hours get reduced I will be forced to find another job since bills have to be paid. As a result I would need approval for my son for around 70h weekly. This is way more than the state is currently paying me. I would have to find multiple people to take care of my son, which is a job in itself. I have advertised in multiple places and no one even responded to the advertisement. The job is so demanding and the pay is so low that no

one is willing to do it. Therefore we will be **FORCED** to put our non-verbal, g-tube dependant, risk for falling son into a group home. That would cost the state even more money!

As you know the institutions and government of Virginia have not been disability friendly. People with disabilities have been treated horribly and have been dehumanized. As our loved ones suffer, we, as families, have decided to change that but we are paying the price we can't carry ourselves. DMAS is basically forcing families to live either in poverty as it's extremely hard to find reliable attendants who would take care of individuals with disability and we are one income family or basically forces us to put the individual in a group home against the individual's wishes. This is an atrocity!

On an emotional, social, and economical level what DMAS is doing does not make any sense. It doesn't make sense on the human level most of all.

I'm appealing to you to **PLEASE** see that what DMAS is saying and what they are doing to us as families already burdened with tremendous emotional and financial heartache are two different things. We are not getting the help and support that we need. We are in constant fear that our hours will be cut, not approved or removed all together. We love our children but the stress is tremendous.

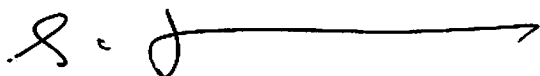
To summarize:

Please require DMAS to **give the individual with disability the choice as to whom to hire as an attendant, that includes both single and married parents, and spouses** without putting extra burden on them of proving that outside help needs to be offered that position first.

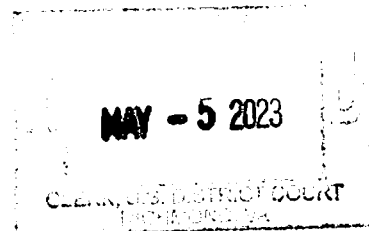
May the **hours that are required for help be based on the individual's needs**, not the unpaid caretaker's work schedule.

Let companion or **respite hours be performed by individuals who are 16 years old** (rather than 18) which will allow both the paid and unpaid caretaker to have a little respite together and other family members like siblings would be able to help out.

Thank you for your work and your attentiveness to this very sensitive issue,

A handwritten signature in dark ink, appearing to read 'Anna Swanson', followed by a long horizontal line extending to the right.

Anna Swanson



May 2, 2023

Honorable John A. Gibney, Jr

701 East Broad Street

Richmond, VA 23219

To Whom it concerns:

I'm writing you about the Settlement agreement for people with disabilities. My Daughter receives services and they are desperately needed for her. Please do not end the agreement until Virginia has reached compliance and sustained compliance for a period of time that demonstrates the long-term capability to maintain compliance.

I understand the position of the commonwealth that they will achieve. Please hold them accountable.


Denise King

7661 Greenwood Way

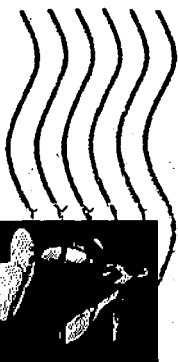
Nokesville, VA 20181

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Denise King
7661 Greenwood Way
Nokesville, VA 20181

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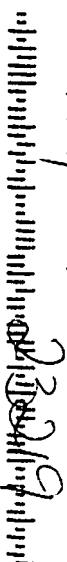


DELIVERED
STATION

Honorable John. M. M. M.
701 East Broad Street

Richmond, VA

23219-183399



May 3, 2023

The Honorable John A. Gibney Jr.
701 East Broad Street,
Richmond, VA 23219

Dear Judge Gibney,

I am writing to discuss how the **Commonwealth of Virginia is not ready to end the settlement agreement.**

More than a decade ago, the Commonwealth of Virginia entered into a settlement agreement with the U.S. Department of Justice (DOJ) to ensure Virginians with developmental disabilities had access to high-quality community-based services. The Consent Decree between the DOJ and Virginia was originally set to expire on June 30, 2021. But because Virginia had failed to meet all the requirements set forth in the decree, the federal court extended the date to December 2023. Virginia's goal is to exit the agreement by December 2023. I am writing to you to express concerns about the settlement and its inadequacy of monitoring systems, transparency, and assurances of health and safety for people with the most complex needs.

I have four grandchildren diagnosed with autism - all of them vary. My grandson, Alex, is 17 years old and is non-speaking and also medically complex. My grandson, Zachary, is 14-years-old and is minimally speaking. Both will need 24/7 care for the remainder of their lives.

In reviewing the data from the Department of Justice (DoJ) settlement, I believe there are multiple areas of concern. First, as seen in the screen shot below, the number of people living independently is not nearly enough- the target was 1,866 and the actual is only 1,654. All of my grandchildren want to live in the community (with the needed supports) – not institutions nor group homes.

Independent Housing

Number of People Living Independently

Fiscal Year	Target	Actual Outcome	Target	Actual Outcome
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As seen in the screen shot below, the independent reviewer's look behind in 2022 for people with complex medical needs (like my grandson, Alex) fell very short in many areas (highlighted in the red box below). The negative data are extremely concerning to families like mine.

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Source: Behavioral Support Report found DOJ LIBRARY
<https://doj.solutions.courtsystem.virginia.gov/dojapplication/provision/nr.c.6.n/>

People with Complex Behavioral Needs

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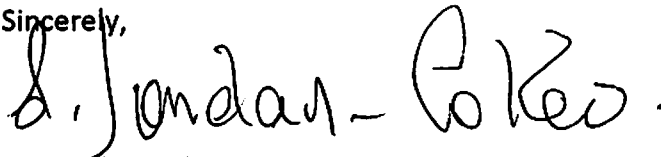
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Again, I feel very strongly that the Commonwealth of Virginia is not ready to end the settlement agreement. As the presiding judge monitoring this settlement, I implore you to

extend the date of decree for this settlement so Virginia can meet the multitude of targets it has not met to date. Virginia needs to get this right before they wash their hands of it.

Thank you for your time and attention. Please do not hesitate to contact me with questions or requests.

Sincerely,

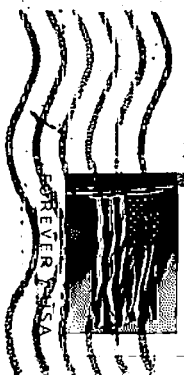
A handwritten signature in black ink that reads "Lyn Jordan-Coker". The signature is written in a cursive, flowing style.

Lyn Jordan-Coker
404 Short Street
Ashland, VA 23005
804.240.1707

Lyn Jordan-Coker
404 Short St
Ashland, VA
23005

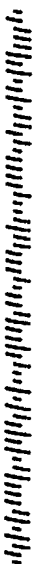
The Honorable John A. Gibney, Jr.
701 East Broad St.
Richmond, VA
23219

RICHMOND VA 230
8 MAY 2023 PM 4 L



INSPECTION
MARSHAL'S
OFFICE
UNITED STATES
DEPARTMENT OF JUSTICE

23219-183399



Jessica S. Burmester
7416 Spring Village Drive Apt 301
Springfield, VA 22150

May 1, 2023

The Honorable Judge John A. Gibney, Jr.
701 East Broad Street
Richmond, VA 23219

Dear Judge Gibney,

I am writing to ask you to extend the expiration of the Consent Decree between the U.S. Department of Justice (DOJ) and the Commonwealth of Virginia beyond the proposed expiration date of December 2023.

The Commonwealth of Virginia has not met all of the requirements set forth in this Decree. Virginia has closed its state training centers for people with intellectual and other developmental disabilities but has not yet provided equivalent services in the community for those most profoundly disabled. Finding and keeping qualified staff is problematic due to the high cost of living in Northern Virginia and the inadequate Waiver rate differentials. High staff turnover is an indicator of poor quality of care. Our most vulnerable citizens deserve more than this.

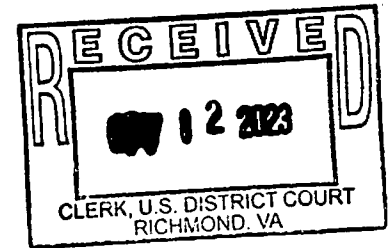
Since the Northern Virginia Training Center (NVTC) closed, there is no system of last resort in our community and there are few options for individuals who have severe and profound disabilities. Most of the providers in Northern Virginia cannot currently provide adequate services for my son, who is 54 years old and has profound intellectual disabilities and autism. He also has several physical disabilities including dysphagia, scoliosis, kyphosis, glaucoma, cataracts, brittle bones due to osteomalacia, hypothyroidism, chronic kidney disease, and myelodysplastic syndrome. He needs a group home that can provide appropriate supervision of his health care needs and provide medical attention when needed.

To help you understand what is lacking in the current array of services, I will briefly describe my son's history of services and medical needs. My son lived at home until he was twenty-two. He then moved into NVTC because of the lack of resources in Fairfax County. He lived there until 1996 when, due to a previous Consent Decree between the Commonwealth of Virginia and the DOJ, he was able to move into a group home using the newly created Virginia Medicaid Waiver for individuals with developmental disabilities. He has lived for twenty-two years in his current group home, which is operated by the Fairfax-Falls Church Community Services Board (F-FC CSB).

Over the years, my son has suffered multiple fractures due to his osteomalacia. In 2018, he started using a wheelchair after a partial hip replacement to repair a fractured hip. Recently he had a periprosthetic hip fracture and spent nine days in Fairfax Hospital over Thanksgiving. At the hospital he developed aspiration pneumonia. It seemed to clear and he went home, but the pneumonia returned. Two weeks later he went back to the hospital for twenty-one days over Christmas and New Years. He was close to death on Christmas day. Fortunately, over the next few days, he recovered from the pneumonia and was ready for discharge the first week of January.

A zoom team meeting was held while he was still in the hospital to determine the next steps. Both his direct care staff person and his group home manger stated that they could not meet his needs at the group home. Upper management on the call asked the team to reconsider and see how they could support him. It turned out that we had discussed using hospice care if his condition worsened, and that was the reason the group home staff were reluctant to take him back. The group home does not serve anyone on hospice care nor would they serve anyone who had a feeding tube. Since those things were not put in place during his hospital stay, he was allowed to return to his group home on January 5, 2023. He is currently eating well, maintaining good health and getting stronger.

The fact that his group home of 22 years could refuse to take him back was startling news since his group home is run by the F-FC CSB. I was totally flabbergasted to realize that my son could have been left in the hospital until the



state found him another residential placement – anywhere in the state! This could mean that he would lose weekly contact with his family, who love and care for him, and whose presence is especially critical when he is hospitalized. Given my age, I do not have many more years with my son. I want him to be nearby so my daughter and I can provide the oversight he needs when he is not well.

I asked his case manager to help me look into medical homes in Fairfax County only to find that she was leaving at the end of 2022. I was told that 80% of the F-FC CSB's case managers are new to the field; his new case manager would be inexperienced. I asked the case manager's supervisor to become involved. My daughter and I began to investigate other residential options for him since his current group home could discharge him if he was hospitalized again, a likely occurrence given his health conditions.

Many of the houses we looked at recently are, in my opinion, highly unsuitable, even if they have what appears to be adequate nursing supports. The Commonwealth may have certified nursing agencies to provide Waiver services, but they neglected to take into account the real physical, medical and emotional needs of their most disabled citizens as well as the importance of suitable, adequate housing. Here is what we found in our investigation:

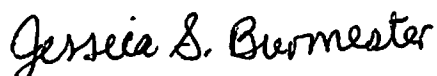
- The Burke ICF run by CRI, which was designed to take some of the last remaining residents at NVTC, does not serve anyone who has a feeding tube. They have a new house with a good accessible layout and nurses on staff, however, they have no openings right now.
- The Arc of Greater Prince William's Insight (GPW/Insight) program was the only provider we looked at that had a good nursing staff and completely accessible homes. They had an opening in Woodbridge but nothing in Fairfax County. Unfortunately, he was not a good match with the other residents in the home. They will continue to consider him for future openings.
- Another provider, Scarlett Haven, serves very medically handicapped individuals, has excellent nursing services, and has homes designed for former NVTC residents. However, the rooms in both of the homes we looked at were not large enough for someone who can move their wheelchair around the house independently. They are keeping him in mind for future openings in other more suitably configured homes.
- Several of the agencies that provide nursing support and are certified to provide the nursing care my son requires, had homes that were either not accessible for someone using a wheelchair or the home was too small to allow anyone using a wheelchair to move independently around in the house. Some of the houses were abysmal. One provider told us their home was accessible but at our visit there we found that the pathway into the house was difficult and had sharp turns. In some houses the bath rooms and living rooms were extremely small. Several other providers on the list did not return my calls. In addition, the individuals living in most of the homes we visited were higher functioning both mentally and physically than my low-functioning, non-verbal son, which poses a risk for him.

— So, that's my story – there is nothing in Fairfax County right now that meets his needs and not much in the surrounding counties. I'm left with no more places to explore, no options, and if the settlement ends, the state's motivation to support people with the most complex needs is only likely to wane.

Is it asking too much for him to have a community-based home in Fairfax County that meets both his health and safety needs plus his desire to be as independent as possible?

Please keep my son in mind as you decide when to terminate the Consent Decree. I appreciate your consideration of my request for an extension of this date.

Sincerely,

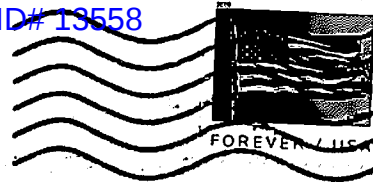


Jessica S. Burmester

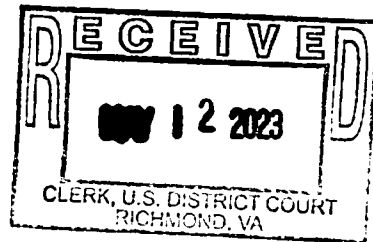
7416 Spring Village Drive, #301
Springfield, VA 22150

NOVA 220

9 MAY 23 PM 02



The Honorable John A. Gibney, Jr.
701 East Broad Street
Richmond, VA 23219



23219-183399



Jane Stanley
508 Shepherd St.
Fredericksburg, VA 22401

April 19, 2023

The Honorable John A. Gibney Jr.
701 East Broad Street,
Richmond, VA 23219

Dear Judge Gibney,

As you know, the Commonwealth of Virginia has been under a settlement agreement with the U.S. Department of Justice for over a decade to ensure that Virginians with developmental disabilities had access to high-quality community-based services. I am surprised and grieved to hear that Trial Attorney Kyle Smiddie has outlined plans for the agreement to formally end at the close of this year. As a parent of a disabled child who has resided in Virginia for the past five years, I can assure you that Virginia does not meet the federal standards that ensure that those with disabilities can live safe, healthy, productive lives.

My son Charlie, who just turned twelve, was born with a chromosomal deletion. He was diagnosed with Smith-Magenis Syndrome which includes a wide variety of health and development concerns including developmental delays, intellectual disability, sleep disturbances, self-injurious behavior, and extreme behavioral difficulties. In spite of his struggles, he is a great kid with a lot of potential. He has a wonderful sense of humor and is intensely social. One of his siblings once remarked that he is "the treasure of our family." Raising a child with a significant disability is never easy, but I have been dismayed at just how difficult it is in Virginia. Though Charlie's syndrome is rare, I am grateful to live in the age of the internet where I can easily connect with other parents who have children with the same syndrome. It has been disappointing to compare notes and to realize just how unfriendly Virginia is to people with disabilities. Though I am a college-educated individual who has worked in several administrative positions, I find navigating Virginia's waiver program one of the most frustrating experiences of my life. There are few places where one can find clear answers to simple questions, the rules are always changing, and employees of these programs are often misinformed. The program rules are full of contradictions. Perhaps the most striking one to me is that I have been repeatedly told that if one does not "use the waiver services" (by which is meant, finding an attendant), then you risk losing the waiver. However, the program requirements of hiring an attendant take an arduously long amount of time, and the mandated pay is extremely low. It is nearly impossible to find an attendant who is able and willing to manage Charlie's behaviors and accept the low pay. In fact, there is a good chance they will work for a month or more without being paid because it takes so long for the paperwork to get filed. And yet, the program rules state that if Charles is not "using the waiver services," they presume he must not need them and he risks losing all services. In fact, the program rules punish the members with the highest needs.

My family was overjoyed when Appendix K was passed during the pandemic. It allowed us to finally adequately care for Charlie's needs. My husband has served as his attendant for the past three years. I don't need to spend weeks training my husband-- he knows Charlie's needs and how to best care for him. I don't need to worry that Charlie will be abused and unable to report it, and I don't need to worry whether or not my husband will show up on any given day or quit at a moment's notice! Before this flexibility existed, we were constantly struggling to find attendants so that we could work. It only makes sense to offer parents the option to be a paid caregiver for their disabled children. How can they work if they can't find reliable care for their high needs child? How can they find reliable care if the wages are so low? The program administrators treat parents as if they are criminals trying to "game the system." They claim that parents should not be paid to care for their own children, and that there is not sufficient oversight. However, if a child is evaluated and found to need a certain number of hours of attendant care (in other words, care that goes over and above the needs of a typical child), why does it matter whether a parent serves in that role or a random hired attendant? Do the program administrators really think that a child is going to receive worse care under a parent than a stranger? Additionally, my question remains: what happens when an individual's needs are so high that no one except a parent will care for them? It seems the program administrators are content to say "too bad." Many people advocated for the Appendix K flexibilities to remain permanent, and it was included in the state budget in 2022. However, DMAS now seeks to place more hurdles in the way of this flexibility. Parent attendants will only be allowed as long as they are employed by an agency. An hour spent calling local agencies revealed that no agency would hire a parent to only care for their own child, the pay would be even less to cover the agency fees, and parents would have to spend weeks or months and hundreds of their own dollars in order to be trained by the agency. I hope that I am conveying that DMAS is making this flexibility possible on paper, but impossible in practicality. What parent of a disabled child has that kind of time and money? And again, the agencies are saying they would not hire a parent to care for their own child.

I only briefly mention the other indicators that Virginia is not ready to exit DOJ oversight: the staggering number of individuals stuck on waiver wait-lists for years despite needing care now, the shortage of care workers and their high turnover rate, the lack of agencies and service facilitators. The fact that Virginia has made such little progress in such a long amount of time suggests that even greater oversight is needed. Please do not send the message to disabled Virginians and their families that what little improvements have been made are enough. Those improvements clearly fall short of the national standard. I know Virginia can do better, but it clearly needs continued oversight and pressure to do so.

Thank you for your time,



Jane Stanley

Stonely
508 Simpson St.
Richmond, VA 23401

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MAY 17 2023
CLERK, U.S. DISTRICT COURT
RICHMOND, VA

The Honorable Judge A. E. Davis
701 East Broad St.
Richmond, VA 23219

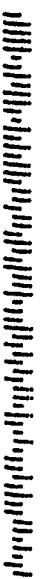
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RICHMOND VA 230

MAY 2023



23219-183399



Barbara S. Osgood
8812 Victoria Road
Springfield, VA 22151

May 14, 2023

The Honorable John A Gibney, Jr
U.S. District Court for the Eastern District of Virginia
Richmond Division
Spottswood W. Robinson III and
Robert R. Merhige, Jr., Federal Courthouse
701 East Broad Street
Richmond, VA 23219

Re: Civil Action No. 3:12cv59-JAG

Dear Judge Gibney:

I am the mother of a young man who has benefited from the Settlement Agreement in the above referenced case. However, I have friends and have met other parents whose children in Virginia are still in need of supports that the continuation of supervision of the Settlement Agreement by your court could facilitate.

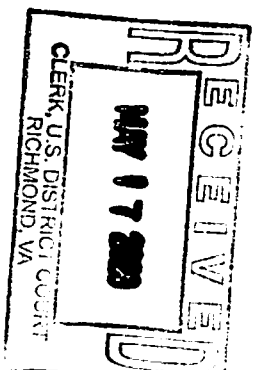
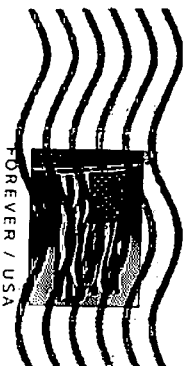
I know that the Commonwealth has projected that it will be in compliance with the Settlement Agreement by December 31, 2023. I am concerned that Virginia will argue that it has complied with most of the requirements of the Agreement. I urge you not to declare the case closed until Virginia is in full compliance with all the requirements of the Settlement Agreement.

Respectfully yours,

A handwritten signature in black ink, appearing to read "Barbara S. Osgood", with a long horizontal flourish extending to the right.

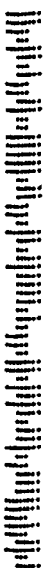
Barbara S. Osgood
8812 Victoria Rd
Springfield, VA 22151

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15 MAY 2023 PM 7 L



THE HONORABLE JOHN A GIBNEY, JR
U.S. DISTRICT COURT FOR THE EASTERN DISTRICT OF
VIRGINIA
RICHMOND DIVISION
SPOTTSWOOD W. ROBINSON III AND
ROBERT R. MERHIGE, JR., FEDERAL COURTHOUSE
701 EAST BROAD STREET
RICHMOND, VA 23219

23219-183339



Your Honor:

My name is Sandra Silvers. I am the mother of a thirty three year old son, Robert, who is diagnosed with several disabilities. I was appointed his legal guardian when he was eighteen years old. This letter is lengthy because my son and I have been living in a nightmare for the past month. Many things have happened that should never have occurred. I had to fight to get the help my son needed that should have been provided. I need to make you aware of what happened to my child because he is mentally ill.

On February 25, 2023 he had behaviors that necessitated him having to be transported to Sentara Rockingham Memorial Hospital in Harrisonburg, Virginia. While on the emergency ward I talked with several people. All of the employees were wonderful but I was told he could not stay there because the psychiatric unit at the hospital did not treat individuals with dual disabilities. I had an employee contact REACH. I was terrified of what was happening to my son. I was told by the REACH employee not to take him home with me because it would not be safe. He said the hospital had to keep him if I told them I was unable to take him home. I left the hospital around 4:00 AM on Sunday,

February 26. A psychiatrist from the hospital called around 5:00 AM to talk about medications. Since it was Sunday many of the people I needed to contact were not in their offices. I spent a long time with my son that day. During that time Daniel from REACH contacted me and said there would be a meeting on Monday the 27th with the CSB, REACH, Robert and me to determine whether or not Robert would be able to go to the crisis house after he left the hospital for two or three weeks as a transition to coming home.

February 27 I arrived at the hospital around 9:45 because I did not know what time the meeting would take place. Laurie, from CSB, asked me some questions and then told me she would come get me when the meeting took place. I did not see her again until a little after 12:00 PM. She asked more questions and left. That was the last I ever saw her.

Around 2:30 I asked a nurse to see what was happening. She left and returned and said the room the CSB used had its door closed. She gave me the number to call the CSB. I was transferred to the person with whom I had talked at the hospital. They had had their meeting and she had left without involving me and I had been in the waiting room six hours. I was irate.

I called the director of the CSB but she was in a meeting. On February 28, she returned my call and said she would address the situation with the employee because that was unacceptable. After I finished talking with her Daniel from REACH called and said that they had found Robert eligible to go to the crisis house when he left the hospital but he had to agree to it.

Meanwhile, I continued to meet with many different people. Ellen, from PERS told me that they could not treat Robert there and they were looking for a bed elsewhere. She eventually told me that they had contacted every hospital in Virginia with psychiatric wards and none treated individuals with dual disabilities. They had started looking at state hospitals. She said they would let me know when they found one.

March 7

I had another meeting with REACH. This worker found Robert ineligible to go to the crisis house after leaving the hospital because she asked him if he wanted to go to REACH house. He told her no. He did not understand that she meant for awhile. He thought she meant going there to live and he wanted to come home.

March 10 around 3:00 I went to visit Robert. I was surprised to see another patient in his room. The nurse told me that Robert had been transferred to Northern Virginia Mental Health Institute at 1:00 AM. I attempted to get in touch with NVMHI but there was nobody available to talk with me. I finally was transferred to Admissions and the lady was very nice but told me she could neither confirm nor deny that Robert was there. She said she would transfer my request to the proper sources but that nobody who could answer my questions would be there until Monday morning. I went an entire weekend without knowing what was happening with my son.

March 13 I received a call from the psychiatric team a little after 8:30 AM. A person on the team told me they had tried to get in touch with me on Friday but they had been given the wrong number so they were glad I called to give them information on how I could be reached. We discussed the plan of treatment. I was agreeable with the plan. I was told that they would be in touch with the social worker to discuss visitation.

March 14 I had not heard from the social worker so I called to talk with her. The person who answered the phone said she would let her know I had called. After a couple hours had passed and I still had not heard I attempted another call. The person who answered the phone said that she had already related the message and that she was only allowed to email them once.

March 15 I attempted to get in touch with the social worker again and was told again that the person would relay the message. I called my son's case manager with the CSB to get some help. My son had been hospitalized five days and I had been able to talk with nobody but the psychiatric team and the person answering the phone. My son's case manager, Anna, told me I needed to quit calling the hospital and let them do their job. Then she told me that since I had the address of the hospital to get in my car and drive there to see him. I remarked that if they would not let me talk with anybody I was sure they would not let me see anybody.

I called NVMHI again and asked to speak with an administrator. The person answering the phone asked me what I wanted with them. I told him that my son had been there since March 10 and I had not been able to talk with anybody and it looked like my son would be discharged before I even would be able to talk with anybody.

At 4:37 on March 15 Pearl, the social worker that was assigned to Robert, called. She said that she had been in training and when she returned she needed to contact the parents of her other clients first. When I asked if she was the only one there she said there were three others but they were covering her clients as well as their own. Then she said that she had to find a time to sit down with Robert to get his permission to call me. I told her he was not authorized to give permission because I am his legal guardian. She said she did not know that. She said she did not have any papers showing that. I told her the papers should have been in with what was sent from RMH. She said they were not there. Then she said she had three more minutes to talk with me. I was irate and asked her if she only had three minutes to deal with my son. She said she got off work at 5:00. Then we set a time for visitation.

March 16 I called the patient advocate at RMH and told her that Pearl had said she did not get the paper verifying that I am his legal guardian. She looked through some papers and said that it had been sent along with everything else. She said she would resend it.

March 29 I contacted Pearl about Roberts discharge

I told her that at the discharge meeting the previous day Grace kept calling it his projected discharge. I asked how that affected his discharge. She said that he would definitely be discharged on Friday. I asked if I drove up there to get him I would be allowed to bring him home. She said yes. Then I asked her about the meds. I told her the psychiatrists were sending him home with a 14 day supply of meds but he didn't have an appointment with his psychiatrist until April 18 and that would give Robert four days without meds. She told me he did not have an appointment on the 18. I told her he did because I had made it myself. She repeated that he did not have an appointment on the 18 because she was the one who scheduled his appointment and she had not scheduled it yet. Then she told me Robert could not be discharged until he had an appointment. He was supposed to be discharged the following day. I had been told by the psychiatrists the week prior that they had talked with his psychiatrist and she had guaranteed to see Robert within a week after his discharge. I was furious. Then she said she had tried calling but they didn't answer. I gave her the name of the psychiatrist and the number to call.

About an hour after I got off the phone I called the psychiatrist office to see if an appointment had been made. I talked with Becky. She checked Roberts appointment and said he had an appointment on the 18. I told her what was going on. She told me to get in touch with Linda. I cannot remember exactly what agency but it dealt with discharges. Becky gave me the number to call. I called Linda and told her what had happened. Linda had been at the discharge meeting on the previous day. She told me that she would call Pearl and tell Pearl she had to take care of it immediately. A couple hours later Linda called me back and told me that Robert had an appointment for April 6.

March 31

A friend took me to pick up Robert. I had contacted Pearl and she told me that Robert would be waiting at the door and for me to call when we were five minutes away. I called as I had been instructed. Then I called when we arrived. She told me she was with a patient and for me to go to the front desk. I called to get in and a few minutes later Robert appeared with an RN. The RN handed me the discharge papers. I told her I was going to read them before I signed them. She told me that Robert had already signed the discharge papers. I told her that he was not authorized to sign anything because I am his legal guardian.

When I reached the section dealing with meds there were two meds listed as to be given once a day. It did not specify when they were to be given. Also, one med was an injection to be given every four weeks. However, it did not specify when the first one was given. I read the section two more times to make sure I had not missed it. It was nowhere on there. I told the nurse I needed the date of when it was given.

She read it and said that I needed to make the appointment. I told her I could not make an appointment if I did not know when the first one was given and the psychiatrists had told me they had given the first injection. She told me she would go find out. She was gone a long time and then returned and said that it would take about 15 more minutes. I told her we had driven 2 1/2 hours to get there and had to drive the same amount of time to get home and I had been told he would be ready when I arrived. She left and returned after 15 minutes and told me the doctor wanted to talk with me. I waited another long time before the nurse practitioner came out, accompanied by Pearl. Pearl was holding the discharge paper signed by Robert..I could see his signature on it.

I told her he was not authorized to sign it because I am his legal guardian. She told me I could sign above his signature. I told her no because he is not authorized to sign it.

The nurse practitioner asked how she could help. I told her that I needed the date of Robert's injection. She looked at the discharge paper and could not find it on there so she said she would go find it. She left and returned with the discharge date and her name and phone number on a piece of paper.

WE HAD ARRIVED AT 12:03 AND IT WAS 1:38 WHEN I RECEIVED THE DATE OF HIS FIRST INJECTION. I then asked when I was supposed to give the meds that said once a day. She said they normally gave them in the morning.

There were many other issues but these are the most pressing. There is absolutely no reason that I had to wait five days to hear something about my son. There is no justification for having him sign a legal document when I have notified the social worker several times that Robert was not supposed to sign anything because I am his legal guardian. The fact that it took one and a half hours to get a date for me is unbelievable. It is a good thing my friend took me because she was able to keep Robert entertained the entire time I was waiting. His case manager from the CSB was no help. She should have called the hospital to find out what was going on. Instead, she told me to quit calling the hospital.

My son came to me as a foster child when he was six and I adopted him when he was nine. I have had to fight most of the time to provide him with what he needs. Because we lack supports in my community he has suffered. There are no day support programs accepting clients who live at home. I have had to fight to get respite. He was in a residential facility for several years. He returned home a year ago. For several weeks I had no time away from him then I was able to get 4 hours a week away from him while he did community engagement. I kept appealing to his case manager to help me find respite. I constantly searched for activities that would interest him. I finally was able to find an agency that would provide three hours a week. Although that was not enough time I was desperate for any time I got. Finally, after my searching I found another organization that would give him 90 minutes. That agency turned out to be the best thing for us because it also provides counseling services. I had attempted to get counseling but the counselors that had been recommended were not accepting new clients. His case manager told me to keep her informed. I do not know how much searching she did but I was the one who found everything he is getting. I was using the 9 1/2 hours of free time a week to search for more free time so I could actually have free time to myself. I finally found another organization where I could get 40 hours of free time a week. This was six months after he came home and from my appealing to local universities and from my searching with very little help from his case manager.

Although what has happened in the past has been horrible the past month has been pure hell. What had happened in the last month proves the incompetence of many people working with the mentally ill. Fortunately, I was a teacher of students with special needs and I had many contacts to help me know who to contact and what to do. There are many parents who do not have that advantage. Since I read the discharge papers I discovered the missing date. Many people do not read before they sign anything because the packets are too long and difficult to understand.

What happened to my son should never have happened. The fact that it was not honored that I am his legal guardian is serious. The document proving I am his legal guardian is a legal document and it was not honored. Robert is not capable of making decisions that relate to his well being. Also, the entire medicine mix up could have caused serious illness in my child. The fact that I had to wait for an hour and a half was a violation of my son's rights. He had to wait until I had finished before he could leave. Waiting is difficult for him and he had to wait an hour and a half.

I realize this was lengthy but what happened needed to be explained in detail so you could see the seriousness of the events.



Sandra F. Silvers

On Monday, April 3, 2023, 09:34:42 PM EDT, Sandi Silvers <ssilvers99@aol.com> wrote:

Admitted to RMH

Called REACH

No beds because of dual diagnosis

Transferred at 1:00 AM and I was not notified although I am legal guardian

I was not able to talk with anybody until Monday morning

I was but able to talk with his social worker until Wed.

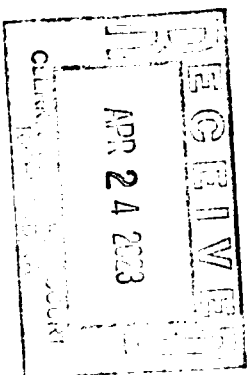
I was told by psychiatrists he would be coming home with 14 day supply of meds and that they had talked with his psychiatrist and she guaranteed she could see Robert within a week

Two days before discharge I talked with Pearl about discharge date and psychiatric appointment. She had not contacted psychiatrist..I called somebody from the dept of discharge

Picked Robert up he had signed discharge papers.

No date of when he had had his haldol injection. Waited an hour and a half to get the date.

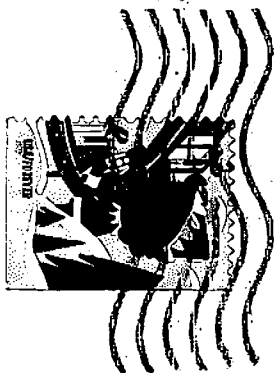
Andrew T. Dierico
6857 Chambers St.
Manassas VA 22802



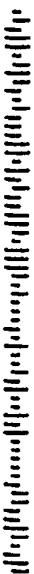
Honorable John A. Dierico Jr.
701 East Broad Street
Richmond, VA

23219

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23219-183359



Douglas Leo Brown
2551 Oak Valley Drive
Vienna, VA 22181

Honorable John A. Gibney, Jr.
701 East Broad Street
Richmond, VA 23219

April 25, 2023

Dear Judge Gibney,

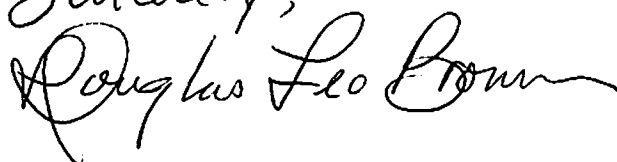
I write to you today as the father of a 41-year old son who lives with autism and mental illness and to request that you continue to hold Virginia accountable to the Settlement Agreement.

Despite my son's need for intensive support in order to maintain his emotional stability and remain free from harm, we only began receiving in-home supports from the Home and Community-Based Services waiver once my wife and I both entered our 70s. We now have an experienced aide who comes to our home five days per week and additional respite hours. This has been a huge help, not only in the day-to-day life of my wife and I, but especially to better learn the supports our son needs and can receive from others. Without the force of the Settlement Agreement, I doubt that the legislature would have passed the budget needed to make these services available.

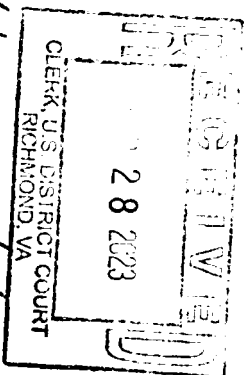
In the past our son was caught up in the criminal justice system due to the lack of robust behavioral health services. We continue to provide him with private mental health services, since we have found the REACH services totally inadequate. It seems that a lot more work is needed in that area.

The Settlement Agreement has really made a lot of progress in Virginia. But as an aging parent, I am concerned that there is insufficient infrastructure within the current system to ensure quality services. Some of the elements of a strong infrastructure include adequate funding, particularly to attract a competent work-force, and high quality training for the work-force so that people like my son with more complex needs are able to remain healthy.

You have dedicated many years to this Settlement Agreement, and I expect that you are as anxious to see it to the finish as are the elected officials of Virginia. But I implore you to be sure that the progress made will be progress maintained. Many vulnerable people are counting on that.

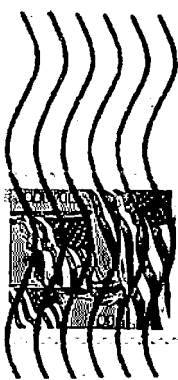
Sincerely,


DOUGLAS BROWN
251 OAK VALLEY DR
VIENNA, VA 22181



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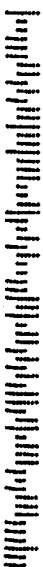
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Honorable John A. Gibbons
701 East Broad Street
Richmond, VA 23219

INSPECTION
MAILED

23219-183333



Honorable John A. Gibney, Jr.

April 16, 2023

United States District Court for the Eastern District of Virginia

701 East Broad Street

Richmond, VA 23219

Dear Honorable Judge Gibney:

I am a friend and advocate for people with disabilities. I live in the beautiful mountains of Southwest Virginia, Blacksburg to be exact. I am very concerned about the end of the settlement agreement. My main concern is the complete lack of providers or agencies and staff to provide the in theory wonderful services outlined in the new waiver design. I would love for the state to work on bringing more people into this profession as a career. By making it a certification or an Associate's degree that could be acquired at local community colleges, similar to a CNA or LPN, which would help workers get a guaranteed level of income and benefits. There's no one to do this kind of work, it is not viewed as a respectable legitimate career. This has created a care crisis! Something big must be done to help intervene!

I think the most person centered, and least restrictive model is the new Shared Living service which hardly anyone can utilize at this point because there are no agencies providing the services. Virginia legislators just increased the funding to this service to make it a viable option. But one thing remains a major hindrance is the requirement that the agency be the landlord. This is a huge conflict of interest. People receiving services should not be getting their services from the same agency that owns their home. If they don't like their services, then they lose their homes?? That is so wrong, it's shameful.

The area where I live is considered a "provider desert". The Arc of NRV was hopeful to start a non-profit agency to become a service provider to complicated individuals who want to live in their owns homes but require 24/7 round the clock supports. As a non-profit, non-funded agency getting this off the ground was impossible. If the state could do a better job helping to get small person-centered agencies off the ground and running it could better meet the needs of people desperate for services that just don't exist where they live.

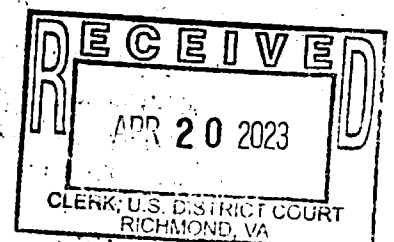
Please don't let the settlement agreement end without these huge needs being met. We are worried that nothing will improve once the oversight ends. Please keep them accountable and the system truly improves for the individuals needing services. As it stands now, improvements have been made in theory, but the lives of individuals requiring services have not.

Thank you sir.



Bayley Alphin

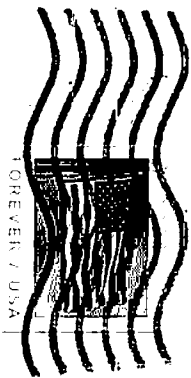
1900 Meadowview Cir. Blacksburg, VA 24060



1900 Meadowview Cir.
Blacksburg, VA 24060

The Honorable John A. Gibley Jr.
701 East Broad Street
Richmond, VA 23219

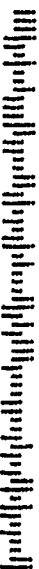
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23219-183399



Honorable John A. Gibney, Jr.
United States District Court for the Eastern District of Virginia
701 East Broad Street
Richmond, VA 23219

Dear Judge Gibney,

Only nine months from now, the Settlement Agreement between Virginia and the Department of Justice is scheduled to end. Although there are many terms of the agreement that Virginia has not adequately addressed, we are particularly concerned that Virginia is woefully short of service-providing agencies to meet the needs of people with disabilities who want to live in their communities.

We are a small group composed of 2 parents of adult children with disabilities, a Direct Service Provider and an advocate for people with disabilities. We call ourselves the Dream Team. Our dream was to create and run a small service-providing agency whose goal is to provide community-based services for individuals with very complex support needs who want to live in their communities. We spent months working with the Department of Behavioral Health and Developmental Services trying to develop the documents required to be considered for a license. Their website was not user-friendly and we were told repeatedly when we asked for help, that we needed to present our application and supporting documents before the licensing "specialists" could provide feedback. Additionally, the time that the DBHDS takes to approve or reject an application once it is submitted can take not months, but years.

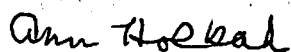
Another significant barrier to starting an agency is the requirement that we have 3 months of operational and payroll costs in the bank prior to approval. Banks are not prone to making unsecured loans to unproven businesses. We had no collateral to offer and no benefactor.

If Virginia and the DBHDS are serious about developing provider capacity, they must demonstrate their commitment to meeting the terms of the Settlement Agreement by providing hands on assistance from the licensing specialists to assist start-up agencies with the required application documents. They must streamline and employ sufficient staff to in order to process applications in a timely manner. Neither the General Assemble nor the DBHDS has made budget requests to make this happen. In order to deal with the three-month cash-on-hand requirement, Virginia could set up a way to secure those loans, for three months until the new agency begins receiving Medicaid payments for their services. Once that happens, the agency can repay the loan.


We are very pessimistic that Virginia has the will to solve this crisis in community-based care in nine months or in nine years. If the Settlement Agreement ends before this capacity crisis is solved, we think we can pretty much give up our dream. Don't abandon our citizens with disabilities.

Sincerely,

Christine Cadwallader 

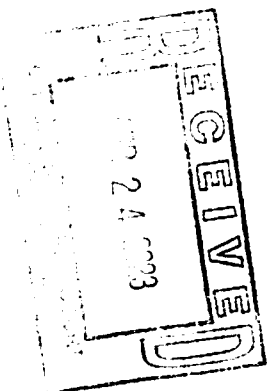
Ann Holbach 

Bayley Alphin 

Catherine McCoy 

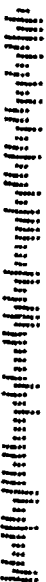
GREENSBORO NC 270

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The Honorable John A. Gibley, Jr.
US District Court for the Eastern District of Virginia
701 E Broad St.
Richmond, VA 23219

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Honorable John A. Gibney, Jr.
United States District Court for the Eastern District of Virginia
701 East Broad Street
Richmond, VA 23219

Dear Judge Gibney:

The Settlement Agreement between the Department of Justice and the State of Virginia is currently scheduled to end in December 2023, only 9 months from now, and Virginia has not yet reached compliance with all the terms of the Agreement. It is the position of the Commonwealth that they will achieve compliance by December 2023. Those of us in Southwest Virginia are not so optimistic.

The Board of Directors and membership of the Arc of New River Valley have significant concerns about ending judicial oversight until Virginia has met all conditions of the settlement and has demonstrated the capacity to sustain compliance.

Southwest Virginia is a services-provider desert. There are not nearly enough agencies in this area to provide the services needed by current waiver recipients much less to meet the needs of the individuals who will receive new waivers if the Governor is successful in making good on his promise to fund the Priority One waiting list before he leaves office.

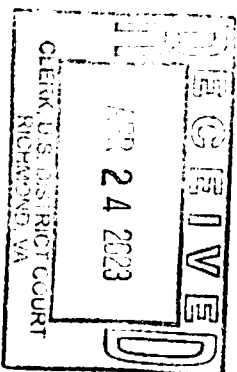
Many people in our area have waivers and no services or insufficient services to live safely in the community. The crisis in availability of community-based supports and services will continue and escalate if Virginia does not target this area until Southwest Virginia reaches adequate capacity to make sure that our people can live safely in their communities.

Under your guidance and stewardship, Virginia has made significant progress in reforming community-based services for Virginia citizens with disabilities. Please do not end the Settlement Agreement before Virginia addresses this woefully inadequate capacity for community-based services that exists in Southwest Virginia.

Sincerely,

Christine Cadwallader
Board President

Adrian Hadar
1417 Highland Circle
Blacksburg, VA.
24060

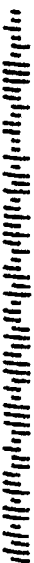


GREENSBORO NC 270
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The Honorable John A. Gibney, Jr.
US District Court for the Eastern District of Virginia
701 E Broad St.
Richmond, VA 23219



23219-352899



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April 10, 2023

The Honorable John A. Gibney Jr.
701 East Broad Street
Richmond, VA 23219

Re: Virginia's Compliance with the DOJ Settlement Agreement

To Whom It May Concern:

With the December 2023 deadline for the DOJ settlement agreement with Virginia to ensure Virginians with developmental disabilities have access to high quality community based supports approaching this year, I'm reaching out to share my ongoing concerns about Virginia's ID/DD waiver system.

As I'm sure you are aware, Virginia continues to miss the mark in terms of compliance in multiple areas. Kyle Smiddie's recent report on compliance to the Arc of Virginia listed multiple areas of continued noncompliance:

- Compliance Indicator #7.8: 86% of children and adults who are known to the system will receive REACH crisis assessment at home, the residential setting, or other community setting (non hospital/non CSB). Virginia's compliance in recent years ranges from 34 – 53%, averaging approximately 41% - less than half of the target.
- Compliance Indicator #7.18: By 3/1/22 86% of those identified as in need of Therapeutic Consultation (behavior supports) are referred for the service (and a provider is identified) within 30 days. Over the period of 9/1/20 – 7/31/22 Virginia's compliance has ranged from 35 – 64%, still significantly below the 86% target.
- Compliance Indicators #7.20 & #29.21: There are 2 parts to this. In #1, DBHDS was required to report the total number of people who needed Therapeutic Consultation in their ISP and how many actually received it. There is no data for this: it was expected in November 22 but DBHDS needed a unique billing code and only created it in September 22. In #2, at least 86% of people who need behavior support services will receive the services that are "adequate and appropriately delivered" (i.e., good quality) using a behavioral quality tool. In FY 22 Q3, based on 100 sets of records, 13% (13/100) were adequate. In FY 23 Q1, 41% (61/150) were adequate. Virginia remains out of compliance.
- Independent Reviewers (IRs) looked back at 32 of Virginia's QSR reviews of 57 people with complex medical needs for services provided January – June of 2021. The IRs found that Virginia's QSRs failed to identify 11 of 15 people in need of dental care, 6 of 7 people in need of clinical assessment/consultation, and 2 of 5 people who needed ISP modification. The IRs found unmet healthcare needs in 22 of the 32 people but agreed with the QSRs that 10 people did not have unmet needs. The presentation noted that numerous required documents in this area were not provided or were not provided in a timely manner.
- 68 people remain in a Training Center and 1770 individuals remain in group homes with 5+ beds.

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The settlement agreement was approved on August 23, 2012. Over a decade later, the 21st report of the Independent Reviewer showed Virginia as noncompliant with 42 out of 126 settlement agreement provisions, or 33% of provisions – a full third of the requirements.

I do not believe Virginia is ready to be released from DOJ oversight and I fear, based on the evidence of noncompliance thus far, that systemic issues have not been addressed and that we will see a reversal of progress made if oversight is removed.

I live and work on Virginia's rural Eastern Shore, where I am the director of our region's brain injury service provider. The noncompliance seen in other parts of the state is magnified here. I have attached a case study of just one individual to illustrate how poorly this system is serving some of our most vulnerable individuals and to share the direct consequences of Virginia's noncompliance. I apologize for its length but hope you will find the time to read through it and hopefully understand the implications as they play out in communities like ours.

In 2014, CMS (Centers for Medicare and Medicaid Services) implemented a federal requirement that states prevent and mitigate potential conflict of interest in case management activities under 1915(c) HCBS waivers. They are very clear that case management (CM) activities must be independent of direct service provision. The only exception allowed is if a state can demonstrate to CMS that the "only willing and qualified" entity or provider of CM activities is also, or affiliated with, a direct service provider, and then there must be established safeguards to ensure individual choice and availability of a clear and accessible alternative dispute resolution process.

Virginia still allows conflict of interest in case management provision by claiming that the CSBs are the only willing and qualified CM providers despite also providing multiple direct services and having a clear conflict of interest. Virginia has published its draft application for renewal of the ID/DD waivers and still is not mitigating this ongoing conflict of interest, nearly a decade after the rule was implemented.

The CSBs are not the only willing and qualified CM providers in Virginia (or wouldn't be if that market were opened up instead of monopolized) and in fact the failure to mitigate this conflict of interest has caused and continues to cause ongoing violations of human rights and individual choice.

I personally believe that Virginia will not successfully meet the provisions of the settlement agreement until they mitigate the ongoing conflict of interest at the very heart of our service provision system. There is no person-centeredness in a system-centered system-controlled world. I hope that you can read between the lines of the attached case study to see the damage being done to real people by Virginia's current system and that you will hold our state accountable until the goals of the DOJ settlement agreement are truly achieved. Thank you for your time and service.

Sincerely,



Rachel Evans

Eastern Shore of Virginia ID/DD Waiver Case Study

“Janet” (not her real name) is no longer an NLES (No Limits Eastern Shore Brain Injury Services) client but our Executive Director visits her in Virginia Beach monthly on a private basis because she has no family involvement and would otherwise be without an unpaid advocate. Janet has a lifelong ID/DD diagnosis and, as of last year, approximately \$150,000 in a trust for her benefit as she was a Dalkon Shield settlement baby. She had cerebral palsy & mild developmental delays in childhood until uncontrollable seizures resulted in her acquired brain injury in her early teens. She has a long history of moderate behavioral outbursts. Her stepfather & primary caregiver died during the early COVID crisis and she and her mother do not get along.

Prior to the stepfather’s death her parents had taken her during early COVID to the local ER twice for help with behavioral outbursts but she was not enrolled as a CSB ID/DD person or provided with any help or crisis support. The Crisis Team only had a record of one of the ER visits. After her stepfather’s death, the situation deteriorated. We were working with her mother to get her on Medicaid because the Eastern Shore CSB would not intake her until she had it but there was another altercation and her mother got a court order for a psychiatric evaluation (she has yelled, cursed, and thrown or slammed things but never injured anyone or caused significant damage).

Sheriff’s deputies came to our day support and took her to the ER, where the CSB employee who heads our local Crisis Intervention Team threatened to have her taken away in shackles due to her verbal threats against her mother. NLES advocated strongly for her, even stationing our case manager at the ER with her, to ensure that she received the protection of her ID/DD diagnosis.

Most of Virginia’s psych hospitals were closed due to COVID and staffing issues, fortunately for her, so she was transferred to a REACH Crisis Home. She remained there for a few weeks with no outburst behaviors and was successful at obtaining an emergency waiver slot. She was discharged by REACH and the CSB placed her in a waiver group home on the Eastern Shore run by a private provider. She was not shown any other residences.

The residence was near No Limits (brain injury day support) but tucked behind a run-down apartment building with no access to the community and diseased feral cats in the yard. After a brief honeymoon, behavior problems arose. The residence owners closed the kitchen to residents at 8pm and required bedtime/lights out by 9pm, violations of HCBS Settings rules which were reported to the CSB Service Coordinator but never addressed. She had repeated outbursts related to sharing a bathroom with a housemate that were never resolved, she had outbursts regarding access to food and chore completion, and even had an outburst because staff told her she could not put her feet on the living room couch.

NLES called meetings with the residence and the CSB Service Coordinator (SC), with one such meeting attended (by phone) by the Eastern Shore CSB Director of DD Services (the direct supervisor of the Service Coordinator, contrary to CMS Conflict of Interest separation requirements). We advocated strongly for a behavior plan and behavioral support, for human rights education, and for resolution of the bathroom conflict. We requested she be given access to internet so she could use the Kindle tablet we supplied her to occupy her time. We requested that someone attempt to access

her large trust fund, managed by her estranged mother, for her benefit. None of this occurred despite multiple meetings and requests.

She told us that someday she wanted to live on her own. We explained her options to her and encouraged and assisted her to develop independent living skills (simple meal prep, laundry, cleaning) to prepare herself, which she was excited about. This angered the group home owners who felt we were pushing her to be independent and blamed us for all of her behavioral issues despite her never displaying outburst behavior at day support. They told this to the CSB psychiatric nurse practitioner who increased her medication but outbursts persisted (this can be found in her medical records).

The CSB Service Coordinator told us they (the CSB) did not feel she would be able to live in a more independent setting and they characterized our concerns as the day support and residence "not seeing eye to eye". Almost a year after her discharge from REACH a behavior support specialist was finally assigned to Janet but it was too late.

Before a plan could even begin to be developed there was an altercation at the group home between Janet and one of the owners. It arose because some of her personal food items (which they required her to store in her room on her dresser) were missing. An argument ensued and staff threatened to call the police and send Janet to jail. She cursed (she states that staff were also cursing), spat at the owner, and slammed the refrigerator door and the owner shoved her to the floor, bruising her tailbone. The owner's daughter, who was also working, told her something to the effect of "if you touch my f***ing mother again I'm gonna mess you up" (note: allowing family groups to run these residences, which is very common in Virginia, creates a significant conflict of interest). The group home owners called the police but Janet was not arrested. We notified APS but they did not find her to be in need of their resources. The group home immediately gave her eviction papers, which she signed (she is self-consenting), and then refused to share them with NLES despite Janet's consent and request.

We informed the Service Coordinator that the residence was refusing to share her documents despite her consent. We were advised that the residence didn't see why we'd need the documents since we are "just a day program". The CSB Service Coordinator said the residence had shared the documents with her and suggested we have Janet call her & request them & she would give them to Janet and then Janet could give them to us.

Janet was given 30 days notice on the eviction and the CSB SC took her to see a couple of residences across the Chesapeake Bay, as due to multiple group home closures there are generally few or no group home vacancies on the rural Eastern Shore (and fewer to serve any behavioral or medical needs) and a number of local individuals with ID/DD have been relocated "across the bay" – a 17.5 mile tolled bridge tunnel separates the rural ESVA from urban Tidewater and creates a significant culture shock and barrier to visitation when people are required to relocate out of their home community.

Janet liked one residence and was willing to move there but then, about a week after the eviction notice, there was another outburst and the residence insisted she be removed immediately. She returned "home" that Friday & all of her belongings were packed up & she traveled "across the bay" with a CSB employee she barely knew to see a residence in Virginia Beach which had an immediate

vacancy. She had no other options, so her CSB SC says she “chose” that home and that is where she now resides. She didn’t even get the chance to say goodbye to her friends. She was just gone.

Our director reached out to DMAS Human Rights by phone and reported the situation and also followed up with new information by email but we never heard any more from DMAS and there is no indication that the Eastern Shore private residential provider or CSB were required to mitigate their ongoing human rights and HCBS settings rule violations.

The new residence and Eastern Shore CSB SC (who remains her SC despite her relocation) were told, in writing, that now that she resides out of our service area our ED (Rachel Evans) will privately serve, by Janet’s enthusiastic consent, as her “person”, her advocate in lieu of family. It was requested that as her “person” Ms. Evans be notified of anything a family member would be notified of. Ms. Evans has never been notified of anything by the CSB, not since the first email saying she had “chosen” a residence.

Janet’s new group home is much kinder and more professional than the one on the Eastern Shore. It is clean and neat and Janet is happy there. Human rights issues continue – for example, they allow a male resident to have ‘sleepovers’ with Janet, where they share a bed on Friday nights, but will cancel said sleepovers based on behavior – but overall it is a better place.

NLES referred Janet to the Virginia Beach brain injury support provider, where she would be eligible for brain injury-specific case management and clubhouse services. When the ABI (Acquired Brain Injury) Case Manager called the CSB SC, she was told that case management means different things to the CSB than it does to brain injury providers. Janet was never shown the local ABI clubhouse, despite having attended brain injury-specific day support for several years. Instead of working in a clubhouse on productive activity she attends an ID/DD day program where there’s a lot of community integration. Janet enjoys going to movies and lunch with her day program, but she was never even offered the choice to attend supports she is eligible for (and probably better suited to, as Janet is a very bright woman who is able to read & comprehend full novels, despite her cognitive challenges).

Her trust fund has still not been accessed for her benefit, a year and a half after leaving her mother’s home, although the residence has indicated that they will pursue it. The CSB has done nothing to help her access these funds, which are in a special needs trust for her benefit. Despite her history of outbursts, REACH involvement, and eviction due to behavior she still does not receive behavioral supports. Interestingly, she hasn’t had any significant behavioral issues in her new residence, just as she never had any at No Limits during her years of attending brain injury day support full time. Janet can be reasoned with and responds very well to being treated with dignity and respect (and very poorly to being treated unfairly or without respect).

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The Honorable John A. Gibney Jr
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